

Guide to Chapter 8

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CHAPTER 8

Supporting Informal Caregiving¹

Informal care is given without monetary compensation to persons who are ill or have disabilities, by families, friends, and neighbors. Informal caregivers provide enormous support to people of all ages and are the backbone of the nation's long-term care system. Active support of informal caregiving aids in keeping families together and avoids the high costs that are inevitable when individuals must rely solely on paid caregiving. Consequently, it is crucial for states to formulate policies that support and sustain informal caregiving. The Medicaid program gives states options that can strengthen and support informal caregiving. This chapter explains what options states have under current Medicaid law to do so.

Introduction

One in three Americans can expect to spend some time over the course of a year caring for family, friends, and neighbors without payment. This adds up to 52 million caregivers a year, helping 37 million family members and 15 million friends. These informal supports are referred to as informal caregiving in the service system for elderly persons and as family supports or natural supports in the disability community.²

Caregiving responsibilities are assumed by adults of all ages. But most informal caregivers are in middle age and almost three-quarters of primary informal caregivers are women. Up to age 70, women are more likely to be caregivers and to care for more than one person. They also provide more hours of care on average and more care over longer periods. The gender gap narrows at older ages, however, as the share of informal care provided by men increases.

The most frequent recipient of long-term care provided by an informal caregiver is an older person (age 65 or older). According to the 1994 National Long-Term Care Survey, over seven million Americans provide 120 million hours of informal care to about 4.2 million elderly persons with functional limitations each week. The estimated economic value of these hours of informal care ranges from \$45–\$96 billion a year.

About one in five elderly persons with functional limitations who receive informal care in the community (780,000) are SSI/Medicaid eligible. They receive on average 34 hours of unpaid help a week from an estimated 1.9 million informal caregivers. Nearly half (380,000) are as severely disabled as most nursing home residents—requiring assistance with three or more personal care tasks or having severe cognitive impairment. These "nursing home eligible" elderly persons on Medicaid receive an average of 52 hours of informal assistance a week.³

Roughly 4 million Americans of all ages who have mental retardation or another developmental disability also live in the community. Half a million of these live with parents over age 60, and this number will grow as the population ages. Only 10 percent of these noninstitutionalized individuals currently receive specialized residential services.⁴ Nearly all the rest live with their families or in other living arrangements where families and friends provide continuing informal support.

Access to informal care clearly helps individuals remain in their homes and communities. There are 1.5 million elderly residing in nursing homes compared with 1.6 million elderly who have similar personal assistance needs but live in their own homes or in the homes of their adult children or other family caregivers. Two-thirds of all elderly persons with disabilities living in the community receive only informal care. An even higher proportion of adults under age 65 with disabilities (86 percent) depend entirely on unpaid assistance.⁵

At a fundamental level, informal caregiving is irreplaceable. The pool of community long-term care workers is inadequate and the public resources that would be needed to replace informal care with paid workers would be exorbitant. Yet, we cannot take for granted that current patterns of informal caregiving can be sustained. Of a number of factors that will make it difficult to sustain the same level of informal caregiving, the primary ones are: (a) continuing high numbers of women employed full time; (b) continued growth in the number of people requiring long-term care, mainly as a result of population aging; and (c) an increase in the proportion of persons age 85 and older, the group most likely to need long-term care. As the population ages, primary caregivers (whether spouses or adult children) will be much older themselves on average, making them less able to provide the level of informal care they might have given when younger.

For all these reasons, access to paid help needs to be expanded to more adequately complement the always essential efforts of family and friends. Strategies are needed to help keep informal caregivers from being overwhelmed by the stress of having to bear the whole care responsibility them-

selves. Paid help is also needed when informal caregivers face competing pressures from other family roles and/or paid employment, become ill, or need a break to pursue their own interests. The appropriate combination of informal and paid services can enable a family to continue caregiving over extended periods. Too often, however, paid supports become available only when a breakdown in informal care has precipitated a crisis.

Many policymakers and program administrators worry that expanding access to publicly funded services will result in the substitution of formal for informal care—with government paying for an ever greater share of the assistance that has traditionally been provided by families "for free." It is often impossible to determine, in particular cases, whether publicly funded services are, in fact, substituting for informal care that would otherwise have been available, or whether publicly funded services are necessary to compensate for an unavoidable lack of family caregivers. Controlled experimental design studies such as the National Channeling Demonstration have consistently found, however, that family members who have previously been providing services do not significantly decrease their efforts when publicly funded services become available. According to this and other caregiving research, when formal care is increased the care provided by families also increases. In other words, as care needs expand formal and informal care increase together.

Medicaid-funded home care programs serve both individuals who receive substantial amounts of informal care from family members and individuals who are almost entirely dependent on formal services. Most of the latter group simply have no immediate family or none nearby. They may have no spouse caregivers because they are widowed, divorced, separated, or never-married. They may have no adult children to provide informal care because they never had children at all, or because their adult children live too far away to provide day-to-day assistance. Or they may be in the period of young adulthood, when it is important developmentally for them to live independently from their family, particularly if the family has been providing care for many years.

Federal Medicaid Policy and Informal Caregiving

Federal policies present no substantial barriers to states in using Medicaid dollars to support people with substantial functional limitations who live with their families (and thus, by definition, have access to informal care). There are no Federal restrictions on the provision of HCB waiver services based on living arrangement, for example, other than that the person cannot reside in an institutional setting. The same is true with respect to personal assistance and other services furnished under the state Medicaid plan. Thus, home and community services can be furnished to individuals who live with their families or in their own home just as readily as to individuals who are served in formal living arrangements such as group homes or assisted living.

Whether provided under an HCBS waiver program or under the state plan, however, to be Medicaid-reimbursable the services must address the beneficiary's needs. This means that services cannot be furnished if they principally benefit the "family unit." States can (and most do) offer respite services under Medicaid HCBS waivers. And state programs do provide relief to caregivers from the challenges of continuous caregiving. This is appropriate. While these services clearly benefit the family caregivers, they are provided directly to the beneficiary, and there is no question that they are of principal benefit to the beneficiary.

States have enormous latitude in configuring their eligibility policies to expand access to home and community services for persons who live with their families (parents, spouses, or adult children). Federal Medicaid policy provides particularly important options to states for making such services available to *children* with severe disabilities who live in the family home. Certain features of Medicaid eligibility policies for services under the state plan can pose service barriers for such children unless they live in very low-income households. However, under an HCBS waiver program, a state may expand the financial eligibility of these children for Medicaid services by deciding not to include the income of their parents in the financial eligibility calculation. States may also extend

Medicaid eligibility to children with severe disabilities, irrespective of whether the child will be served through an HCBS waiver program or the state plan, under the Katie Beckett option. (See Chapter 2 for a detailed discussion of financial eligibility options for home and community services.)

Two questions often arise concerning provision of Medicaid home and community services to individuals who have informal caregiving arrangements in place. One is the extent to which informal care is taken into account in conjunction with authorizing the provision of paid services. The other concerns making payments to family members to furnish services.

Availability of Informal Care

There is no Federal requirement that family members provide some minimum amount of care as a condition of service eligibility. Nor is there any stipulation that services may not be furnished if an informal caregiver is present. However, states can and do take into account the *amount* of informal care available to an individual. If a person needs 40 hours of support per week and informal caregivers are available, able, and willing to provide 20 hours, for example, then only 20 hours of paid supports will be authorized.

In practical terms, assessment of the need for paid supports may focus on specific tasks that an informal caregiver who lives with and is regularly available to assist the beneficiary is unable to perform. For example, an elderly spouse may be too frail to assist his wife with transferring into and out of bed, getting into and out of a wheelchair, or giving other forms of assistance that involve lifting and physical support.

Consideration may also be given to the kinds of household tasks family members typically expect to share or to do for one another when they live in the same household—as opposed to intimate personal care tasks that individuals normally do for themselves. Thus, many state programs expect that spouses, parents, or other adults who do not have disabilities and who live with the Medicaid service beneficiary will take responsibility for general household maintenance tasks. If she lives

in her daughter's home, for example, an elderly mother who requires assistance with bathing, dressing, and toileting and who is also unable to perform housekeeping tasks would, in many states, be eligible only for assistance with personal care tasks and not for homemaker/chore assistance. If the mother lived alone in her own home, in contrast, she would be eligible to receive homemaker/chore services in addition to assistance with personal care.

Adult children caring for parents may have conflicting responsibilities—such as employment and child care. In such cases, support planning may focus on those times of day and week when adult children are unable to provide informal care (e.g., while they are at work). Similarly, a child with severe disabilities might need after-school care until a parent comes home from work. Formal services provided in tandem with informal care may be viewed as supplemental, as supportive, or as regular respite care, if a beneficiary is receiving extensive informal care. (Formal respite care is provided in addition to the regular services furnished.)

Federal policy allows and encourages the "best practice" of matching home and community services to the unique needs of individuals and the circumstances of their informal caregivers. Thus, states can assess availability of informal caregiving and need for paid care by examining each situation on a person-by-person, household-by-household basis. And when authorizing home and community services, states may take into account the preferences as well as the needs of the beneficiary and the family. For example, when a young adult male beneficiary with a disability lives with his sister and her family, everyone may prefer, for reasons of privacy, to have a paid personal care attendant assist with bathing, whereas in the case of an elderly woman living with her daughter, both may feel that privacy concerns are better served by having the informal caregiver assist with bathing.

Payment of Family Caregivers

Federal Medicaid law permits family members to become paid caregivers unless those family mem-

bers are legally responsible for the care of an individual (i.e., spouses and parents/guardians of minor children). The philosophy underlying this policy is that Medicaid should not pay a spouse or parent for services that most spouses or parents would normally be required to provide without charge. However, states have the option to pay even these family members under certain exceptional circumstances. For example, they may be paid for providing skilled nursing services (for which there is no presumption that the service would "normally" be provided free).

Personal care services

Other than spouses and parents of minor children, states may pay any family members to provide personal care services, including adult children of a parent, parents of adult children, siblings, and grandparents. Friends and neighbors may also be compensated for providing services that would otherwise need to be purchased on behalf of the beneficiary. In California's In-Home Supportive Services (IHSS) Program, for example, about 40 percent of consumer-hired personal attendants are related to the Medicaid beneficiary and an additional 30 percent are friends, neighbors, or other individuals the beneficiary already knows.⁶

In the standard application that states complete to secure Federal approval to operate an HCBS waiver, HCFA has provided explicitly that states may choose whether or not to pay for personal care (or closely related services) furnished by family members who are not spouses of beneficiaries or parents of beneficiaries who are minors. Thus, it is up to each state to decide whether it will make payments to a beneficiary's relatives to furnish personal care/personal assistance, including the circumstances under which such payments will be made.

If they choose to make such payments, states are permitted to establish provider qualifications for family members that differ from the qualifications for agencies or individual contractors who furnish such services. States that require criminal background checks for personal care attendants, for example, may exempt family members. In HCBS waiver programs for people with developmental disabilities, the most recent information

indicates that roughly half the states have elected to make payments to family members who provide personal care services.⁷

There are pros and cons to paying family members to provide services. The most powerful arguments in support of this practice are: (a) it addresses the problem nearly all states are encountering with respect to availability of workers to provide personal care/personal assistance and (b) relatives generally know and care about the person and are familiar to and trusted by the person. When people forgo or give up paid employment to provide care, common sense says they should be compensated.

In addition, on at least some quality measures, according to research findings, consumers who hire family members as their personal care attendants receive better care on average than those whose attendants are unrelated individuals, whether employed directly or through home care agencies.⁸ Iowa's Elderly Waiver Program (enacted in 1989) is an example of a longstanding program that recently (1997) added a consumer-directed option under which beneficiaries may hire family members as personal care attendants.

Frequently expressed concerns about this practice are that (a) payments will be made for care that would be provided for "free" in any case and (b) conflicts and problems might arise if the family caregiver is not performing well. In response to these concerns, many states that pay family members allow such arrangements only when other sources of services are not available and the beneficiary will clearly benefit from the arrangement. In programs that enable consumers to direct their own services (e.g., California's In-Home Supportive Services Program, Michigan's Home Help Program), the freedom to hire a family member, friend, or neighbor is considered an important aspect of consumer choice and control. Again, "best practice" is to work out such arrangements on a person-by-person basis, including identifying any special safeguards that might be appropriate or necessary.

Non-personal care services

HCFA has affirmed at various times that there are circumstances where the most practical way to

Oregon's Use of the Foster Care Concept

In its HCBS waiver program for elderly persons and younger adults with physical disabilities, Oregon enables certain family caregivers who bring HCBS waiver beneficiaries into their homes to qualify as providers of "relative foster care." Oregon has also encouraged the growth of small group adult foster care homes (each with up to five residents) that offer a surrogate family environment. These facilities cater primarily to elderly persons who have cognitive impairment but little need for hands-on assistance with personal care tasks. Many such persons are at high risk of placement in larger, more impersonal, board and care settings or nursing homes, because they do not have family caregivers with whom they can live and they are unable to live alone. Interestingly, only about half the elderly residents of Oregon's adult foster care homes are eligible for Medicaid HCB waiver services; the rest pay privately.

obtain a variety of services might include making payments to family members, especially when services are difficult to obtain from other sources. The rules that pertain to paying relatives to provide non-personal care services are not substantially different from the rules for obtaining such services from other sources. The relative must meet whatever provider qualifications the state may have established and charge no more than any other provider. Here again, HCFA expects that a state will limit payments to certain types of relatives or require a demonstration that the service is not otherwise available, that it may not be obtained as economically, and/or that there is clear benefit to the individual from the relative's providing the service. In the case of individuals who need transportation to attend an adult day health program but live in areas not served by transit systems, for example, a relative may be paid to transport the person to and from the program.

Within the broad parameters of Federal policy, it is up to states to define the particular circumstances under which family members will be paid to furnish services in the home and community. States can take various factors into account, including availability of other sources of the same services, costs of family member services versus costs of purchasing such services from conventional sources, and specific circumstances with

Examples of States' Family Payment Policies

Kansas. Kansas's policy on family reimbursement states that "unless one of the four criteria noted below are met, a spouse or parent of a minor child may not be reimbursed for providing personal care services.

1. Consumer's residence is documented in writing by three waiver provider agencies to be so remote or rural that waiver services would be otherwise unavailable.
2. Consumer's health, safety, or social welfare would be jeopardized and is so documented in writing by two health care professionals, including the attending physician.
3. Due to advancement of chronic disease, consumer's primary means of communication can only be understood by the spouse and is so documented in writing by the attending physician.
4. Written documentation from three waiver providers that delivery of waiver services to the consumer poses serious health or safety risks for the providers, thereby rendering waiver services otherwise unavailable."

Minnesota. Minnesota's regulation states that:

1. "Federal financial participation is not available for personal care or any waiver service when provided to beneficiaries by legally responsible relatives, i.e., spouses or parents of minor children, when the services are those that the persons are already legally obligated to provide.
2. Services provided by relatives or friends may be covered only if the relatives or friends meet the qualifications for providers of care, there are strict controls to assure that payment is made to the relative or friend as providers only in return for specific services rendered, and there is adequate justification as to why the relative or friend is the provider of care, e.g., lack of qualified provider in remote areas. Medicaid payment may be made to qualified parents of minor children or to spouses for extraordinary services requiring specialized skills (e.g., skilled nursing, physical therapy) which such people are not already legally obligated to provide."

respect to individuals and consumers. If states do choose to pay family members, they need to check other state regulations that may inadvertently create barriers to their use. Such regulations may include requirements for attendant training or certification, or for employment by licensed or certified home health agencies.

In other cases, more extensive supports might be needed, due to either the nature and extent of the person's condition or the extent to which informal caregivers themselves are unavailable or unable to support the person. Whether the person lives alone or with informal caregivers is frequently an important consideration. Given comparable levels of need, people who live alone usually require more paid help to complement the support they receive from their informal caregivers.⁹

Services and Supports That Strengthen Informal Caregiving

Since the exact situation of each individual and his or her informal caregivers is unique, the specific services and supports needed to complement and strengthen informal caregiving will differ from household to household. For example, caregivers may be able to provide personal assistance needs in the early morning and evening but need other providers of assistance for most of the day. In this case, the services provided might include adult day health care or a similar program, plus occasional respite on weekends.

Home and community services states may or do offer that are especially important in strengthening informal caregiving include:

- **Personal Care/Personal Assistance.** Most persons with severe functional limitations need help with personal care. States may offer these services to individuals who live with their family or spouse, especially in situations where the person's primary caregiver is unavailable to provide this support (e.g., if she or he works). Availability of personal care is especially important when the beneficiary

lives alone. Informal caregivers may be available to individuals only at certain periods of the day or certain days during the week and paid help can fill in when they are not available. Providing personal assistance enables individuals to continue to have a home of their own or, in the case of younger individuals with disabilities, enables them to set up their own living arrangement as part of their transition to adulthood. For states, supporting individuals in their own homes can be vastly more economical than the alternative of moving to a group home or an assisted living facility, simply because it will keep in place the informal caregiving currently available.¹⁰

- **Respite.** The aim of respite care is to provide informal caregivers (usually relatives) a break from their day-in day-out care responsibilities. At a practical level, respite services differ from personal care services only in that respite is usually furnished on an intermittent basis and explicitly to provide relief to the primary caregiver(s). Respite care, for example, can be provided in order to give parents a night or weekend off periodically from the intense caregiving associated with supporting children with especially severe cognitive and/or physical disabilities or medical needs. It is particularly needed if caregivers themselves become ill.

Respite is also important for spouses or adult caregivers of older beneficiaries, including those with Alzheimer's disease and other dementias. Respite care benefits the individual directly by providing services usually furnished by the caregiver, and indirectly by helping avoid the "burnout" of their primary caregivers. Under HCBS waiver programs, respite can be provided in the family home by bringing a worker into the home while the caregivers are away for a few hours or overnight.

Some states also allow respite care to be furnished at sites other than the family home, including especially designated respite care facilities. This out-of-home respite is used most often when the primary caregiver(s) will be away overnight or for extended periods, or

even to enable the primary caregiver(s) to be at home alone during the respite period.

States may establish whatever limits they elect with respect to the amount of respite that will be available to primary caregivers. Iowa's Elderly Waiver program, for example, specifies that paid family caregivers are not eligible for respite benefits. And it is not uncommon for states to cap the amount of respite at 30 days during a calendar year. Many states do not impose such caps in their HCBS waiver programs, however, leaving the amount of respite that will be authorized to be worked out during the individual planning process, based on the needs and circumstances of the particular informal caregivers.¹¹ Most states permit caregivers to "bank" respite benefits and to use the authorized amount whenever it is most needed. This practice recognizes that since respite is intended to renew the energies of the caregiver (for the direct longer term benefit of the beneficiary), its use should be determined mainly by caregivers. States have the option to permit "banked respite" to be carried over from one year to the next.

- **Home/Vehicle Modifications and Other Assistive Devices.** States have the option via their HCBS waiver programs to offer home and vehicle modification services that are necessary to secure beneficiaries in their present living arrangement. Such modifications may include constructing wheelchair access ramps to the home (regardless of whether the home is the caregiver's or the beneficiary's), modifying bathrooms and other parts of the house to make them accessible, and retrofitting vehicles (e.g., installing a wheelchair lift in a van). In addition, states may authorize the purchase of lifts and other devices that ease the burden of physically assisting an individual to transfer or go up and down stairs.

These types of devices, and other accommodations that benefit the individual, strengthen informal caregiving by making it less taxing for caregivers to assist the individual. There is an enormous variety of devices and equipment that may be purchased through HCBS waiver programs or acquired as regular bene-

Modifications and Assistive Devices Covered in Utah's HCBS Waiver Program

Utah's HCBS waiver program for people with developmental disabilities provides a sense of the wide range of accommodations and devices states may offer through HCBS waiver programs.

Ramps

Lifts/elevators

- porch or stair lifts
- hydraulic, manual, electronic lifts

Modifications/additions to bathroom facilities

- roll-in showers
- sink modifications
- bathtub modifications/grab bars
- floor urinal and bidet adaptations and plumbing modifications
- toilet modifications/grab bars
- water faucet controls
- turnaround space adaptations

Widening of doorways/hallways

Specialized accessibility/safety adaptations/additions

- door-widening
- electrical wiring
- grab bars and handrails
- medically necessary air filtering devices
- voice-activated, light-activated, motion-activated, and electronic devices
- grab bars and handles
- fire safety adaptations
- automatic door openers/doorbell
- medically necessary heating/cooling adaptations

Vehicle adaptations

- lifts
- door modifications
- steering/braking/accelerating/shifting modifications
- seating modifications
- safety/security modifications

Trained and certified canine assistance

- purchase of trained canine
- animal upkeep (dog food, license, tax, supplies)
- emergency and preventative veterinarian services
- training for beneficiary and canine

fits in a state's Medicaid plan. HCBS waiver dollars may be employed not only to make modifications and purchase and install equipment but also to provide for its upkeep and maintenance.

These accommodations are needed whether a beneficiary lives alone or with a spouse or other family member. For example, many states offer "personal emergency response system" (PERS) services. Equipping a person with PERS is an especially economical way to promote continued community presence and avoid institutionalization due to concerns about the person's safety during periods when neither paid nor informal caregivers are present. There are many types of such services, but all enable the beneficiary to summon help quickly in an emergency. When the informal caregiver is at

work or when the beneficiary lives alone, PERS can provide peace of mind to informal caregivers that help can be summoned quickly in urgent or emergency situations.

- **Caregiver Training and Education.** Making caregiver training and education available to informal caregivers strengthens informal caregiving and has the added benefit of helping reduce reliance on costly paid help. Family members often find themselves thrust with little or no preparation into new caregiving roles. Informal caregivers want and would often prefer to support family members without relying on any paid assistance. But to do so, they require help in acquiring the necessary skills.

For this purpose, a state may offer "caregiver training and education" as a distinct service

under an HCBS waiver program. This service may include: (a) underwriting the costs of trainers coming into the home to teach skills and techniques for addressing the beneficiary's needs, so that training can be customized to the individual and the caregivers; (b) underwriting the registration and materials costs for caregivers to attend special training and education classes; and (c) paying the expenses associated with caregivers attending workshops and conferences where they can obtain information that will better enable them to meet the needs of the beneficiary. (These expenses might include conference fees, arranging substitute care while caregivers are away, or paying for personal assistance at the training conference itself if the beneficiary accompanies the caregivers.)

Caregiver training may also be provided under the rehabilitation option. Rehabilitation services in Kentucky, for example, include home visits to: (a) assist family members and seriously mentally ill beneficiaries to practice effective communication techniques to defuse stressful situations that occur in home settings; and (b) coach family members trying to manage a severely acting-out child and to improve their behavior management skills.

- **Day Care.** To accommodate caregivers' work schedules, states may purchase day care services. These may include before- and after-school day care or day camp when school is out. The service can include sending a paid worker to pick up the beneficiary from school and to provide care until the parent(s) arrive home from work. In its HCBS waiver program for people with developmental disabilities, for example, Utah provides "latch key supports" specifically for this purpose. Like any other Medicaid service, such services may be authorized only to the extent that they cannot be obtained from alternative funding sources.

Adult day care services are also beneficial to families providing informal care to older persons with Alzheimer's disease or other dementias, and to any informal caregivers who have an outside job and who are concerned about the safety of a person left alone at home.

- **Family-Directed Services.** Many families prefer to directly manage the services and supports the beneficiary will receive. They want to make decisions concerning the workers who will come to the family or the beneficiary's home to provide assistance. They also want control over the "care schedule." In the case of children with disabilities, the family—not the child—is the decision maker concerning services and supports. In the case of adults, families also may direct services and supports, especially when the individual is unable to do so. In this vein, states may elect to provide families additional assistance in directing services and supports, either through their service coordination systems or by authorizing families to secure the services of "support brokers" or "personal agents" to assist them in managing supports in full or in part. Pennsylvania's Person/Family-Directed Supports HCBS waiver program for people with mental retardation specifically makes this type of support available to families.

Supporting Families of People with Developmental Disabilities

In the area of long-term care services and supports for people with developmental disabilities, there is a long, robust history of state-operated "family support" programs. The aim of these programs is to provide supports that benefit *both* the individual and the family and, thereby, contribute to maintaining and sustaining the family unit. In many states, these programs have been in operation for nearly three decades. Many of the principles, values, and practices that have been incorporated into HCBS waiver programs for people with developmental disabilities are equally relevant in furnishing HCB services to individuals who have other types of physical and mental disabilities and are served in other types of waiver programs. And many states have similar programs targeted to family members providing eldercare, especially to persons with Alzheimer's disease or other forms of dementia. These programs are financed either entirely with state funds or through a combination of funding streams that may include some Medicaid funding.¹²

In addition, many states have taken important steps to support adults with developmental disabilities who want to have a home of their own rather than be served in a provider-operated group living arrangement. These "supported living" arrangements seek to combine paid and informal supports to enable individuals to live as independently as possible in their communities. Until recently, however, many states tended to confine provision of HCB waiver services to persons served in group homes or similar specialized, provider-operated living arrangements.¹³

Two major factors help explain why some states have not employed HCBS waiver financing for family support services. First, until states were given the go-ahead to expand their HCBS waiver programs to whatever level they desired, some states targeted HCB waiver services mainly to persons in the most costly settings. Second, stakeholders in many states have been leery of "Medicaiding" family support services, for fear that the result would undermine a very strong tradition of family control and direction of such services. In some states, for example, developmental disabilities family support programs operate by giving the family a monthly cash stipend. This gives the family complete control with respect to the goods and services they will purchase to meet the individual's and/or the family's needs. Since Federal Medicaid policy does not enable cash payments to be made to or on behalf of beneficiaries, such cash stipend programs have been "off-limits" for Medicaid financing.

But times have changed. States are now being confronted with extremely high demand for home and community services for people with developmental disabilities. Many different factors account for this high demand. One factor is the increasing longevity of people with developmental disabilities, many of whom now live with parents who themselves are elderly and less able to meet the needs of their adult children.¹⁴ Another is that, unlike in the past, it is increasingly common for people with developmental disabilities to outlive their parents. Many states, even those that have substantially expanded the availability of home and community services over the past decade, have very long waiting lists for services.¹⁵

As a consequence, many states are rethinking the role that Medicaid HCBS waiver services might play in meeting the needs of people with developmental disabilities—particularly with respect to broadening availability of such services to individuals who live with their families or where other informal caregivers are providing support. While requests for services and supports often take the form of families seeking a group home placement, frequently (although not universally) in-home and family support services can meet the needs of the person without the person's having to leave the family home. States that make services and supports more readily available to people with developmental disabilities who live with their families in fact experience lower demand for group home and similar services.¹⁶

This rethinking is taking various forms. Some states have launched distinct HCBS waiver programs intended mainly to underwrite services and supports for these individuals. These programs do not offer group home and other standard residential services. Instead, they have been crafted principally to meet the needs of individuals who live with their families or on their own with informal caregiving available to them. These programs usually operate under stricter cost caps than the state's parallel HCBS waiver program, under which traditional out-of-the-family-home residential services are furnished. These stricter caps recognize that individuals have informal caregiving available. They also permit the state to give individuals and families considerable flexibility in selecting the mixture of services and supports that best meets their needs. It is important to reemphasize here that family support must be directed toward serving the beneficiary. Services that are primarily for the benefit of the family are not coverable under a Medicaid HCBS waiver.

Use of such caps helps the state avoid imposing service-by-service restrictions on utilization in order to maintain program cost-effectiveness. The flexibility afforded individuals and families also permits states to reflect many of the principles and values under which developmental disabilities individual and family support programs have operated for many years: namely, that the individual or the family be in a position to make sure that the services and supports they receive have

Examples of Waiver Programs to Support Persons with Developmental Disabilities

Oklahoma. In 1999, Oklahoma launched two HCBS waiver programs for persons with developmental disabilities: one for children who live with their families and another for adults who live with their families. Oklahoma launched these programs specifically to address the needs of individuals who had been wait-listed for services. In launching these programs, state officials also took steps to embody the principles of individual/family self-direction of services. In combination, these programs are expected to make HCB waiver services available to an additional 1500 individuals. The program for children operates under a cost ceiling of \$10,000; the program for adults has a ceiling of \$15,000. The difference in the ceilings recognizes that children will be in school, whereas adults may require day support services.

The program for adults offers the following services:

- homemaker
- respite
- family training
- residential habilitation
- prevocational services
- audiology, physical, occupational, and speech therapy services
- extended state plan services (adaptive equipment, specialized medical supplies, dental services, and transportation).
- nutritional services
- supported environment
- psychological services
- environmental accessibility adaptations

The services offered in the program for children are more limited—especially with respect to clinic services—because they are generally available for children as Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefits through the state's regular Medicaid program.

Pennsylvania. Pennsylvania's Person/Family-Directed Supports waiver program operates under a \$20,000 per year cost cap. In combination with expansion of the state's long-standing Consolidated Waiver program (under which most individuals receive specialized community residential services), this Pennsylvania program is an integral element of the governor's recently announced multi-year plan to substantially reduce the waiting list for community mental retardation services.

Colorado. Since 1995, Colorado has operated Supported Living Services, a waiver program geared to serving adults with developmental disabilities who live with their families or on their own in the community. Under this program, individuals and families have considerable flexibility in selecting and managing their own supports. In some cases, "microboards" have been formed that enable families and friends (the person's "circle of support") to directly manage services and supports on behalf of the individual.

Other states have submitted or are considering submitting applications to operate similar programs.

been tailored to their needs and preferences. Availability of Medicaid funding allows states to offer more robust services and supports to families than has typically been the case with respect to state-funded family support programs, many of which allot only \$3000 to \$4000 to a family each year.¹⁷

Operating distinct waiver programs that target mainly individuals who live with their families has both pros and cons. One of the main advantages is that state officials and other stakeholders are often willing to entertain new approaches to furnishing home and community services when they are creating a program as opposed to modify-

ing one that already exists. Supports and services can be selected that are especially relevant to meeting the needs of people who live with their families, paying particular attention to strengthening informal caregiving. The main disadvantage appears to be the administrative complications associated with operating multiple HCBS waiver programs for the same general target population.

Some of the same purposes can be achieved by including distinct, specially targeted benefits within a single HCBS waiver program. Examples of this approach include:

- **Utah.** In its single HCBS waiver program for

people with developmental disabilities, Utah offers assistance and support services intended to enable family members with a disability, who so desire, to remain and be supported in their family homes. The intent is to prevent or delay unwanted out-of-home placement. Services and supports can be provided either in or out of the home and may include provisions to assist the individual with a disability to obtain community supports. They may also include instructions, supervision, and training to the family/caregiver/individual in all areas of daily living. The supports may also include other activities identified in the individual's support plan as necessary for continued skill development, including:

- behavior supports
- special summer programs
- social skills development
- appropriate leisure time activities
- developing interventions to cope with problems or unique situations
- instruction and consultation for the beneficiary and other family members.

Services can be obtained through providers who have contracts with the state to provide family support services. Alternatively, families may choose the "family choice model," in which the family hires and trains the individuals to provide the supports. In this model, the family may use individuals age 16 and older as direct providers of support.

- **Illinois.**¹⁸ The Illinois HCBS waiver program for people with developmental disabilities includes a supported living option intended for persons who live with their family or on their own. Service plans under this option are subject to a total cost cap of \$18,000 per year. Within that cap, individuals and families may select from: (a) distinct services available only to individuals who select the supported living option (intensive case management, personal care, skilled nursing, respite, and transporta-

tion) and (b) certain services available to other program participants as well (day habilitation, behavioral services, and therapy services). Individuals and families may select the services they want as long as the total cost of the services does not exceed the maximum allowed. The supported living option is a distinct benefit nested in the state's HCBS waiver program. This enables states to define distinct benefits especially geared to individuals who live with their families.

Whatever approach a state takes, it can strengthen informal caregiving by ensuring that all its HCBS waiver programs—regardless of target population—contain a wide, diverse menu of services and supports that are important for individuals who live with their families as well as those who live on their own.

Endnotes

1. The primary contributors to this chapter are Gary Smith, Pamela Doty, and Janet O'Keeffe.
2. Unless otherwise noted, data on caregiving are drawn from the following publication: Office of the Assistant Secretary for Planning and Evaluation and Administration on Aging (1998). *Informal caregiving: Compassion in action*. Washington, DC: Department of Health and Human Services. Statistics on informal caregiving may vary according to the source because researchers use different definitions of caregiving and include different populations in their sample. For example, if one study examines informal care provided to people age 50 and older and another study looks only at care provided to people age 65 and older, there will be differences in the number of caregivers and the estimated economic value of their caregiving.
3. Numbers are based on data from the 1994 National Long-Term Care Survey. Data analyses were carried out by Pamela Doty of the Office of the Assistant Secretary for Planning and Evaluation, U.S. DHHS, and Mary Elizabeth Jackson of the MEDSTAT Group, Cambridge, MA.
4. Larson, S., Lakin, C., Anderson, L., Kwak, N., Lee, J.H., and Anderson, D. (2000). *Prevalence of mental retardation and developmental disabilities: Analysis of the 1995/1995 NHIS-D*. University of Minnesota: Research and Training Center on Community Living, Institute on Community Integration.

5. Tilly, J., Goldenson, S., Kasten, J., O'Shaughnessy, C., Kelly, R., and Sidor, G. (2000). *Long-Term Care Chartbook: Persons served, payors, and spending*. Washington, DC: Congressional Research Service.
6. Doty, P., Benjamin, A.E., Matthias, R.E., and Franke, T.M. (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery. Non-technical summary report*. Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
7. Gary Smith, Director of Special Projects, National Association of State Directors of Developmental Disabilities Services. Personal Communication. June 16, 2000.
8. Doty, P., Benjamin, A.E., Matthias, R.E., and Franke, T.M. (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery. Non-technical summary report*. Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy.
9. According to the 1994 National Long-Term Care Survey, 86 percent of elderly persons living in the community who are as severely disabled as most nursing home residents (three or more ADL limitations and/or severe cognitive impairment) live with family caregivers and, on average, receive 60 hours of informal care per week supplemented by a little over 14 hours of paid assistance. In contrast, the minority (14 percent) of equally severely disabled elders who live alone receive, on average, 29 hours of informal help per week supplemented by 56 hours of paid assistance.
10. In developmental disabilities services, supporting individuals to live in a home of their own is usually called "supported living." Several states offer supported living services in their HCBS waiver programs for people with developmental disabilities, in order to encourage independence and integrated "everyday" living in the community rather than limiting "out-of-the-family-home" services to group living situations. Developmental disabilities supported living "models" include working out strategies to blend "natural supports" (i.e., informal caregiving) together with paid help to enable the individual to live in a home of her or his own. See: Smith, G. (1991). *Supported living: New directions in services to people with developmental disabilities*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.
11. In 1990, Congress amended Section 1915(c) of the Social Security Act to specifically prohibit HCFA from imposing any limits on the amount of institutional respite services states might elect to provide in their HCBS waiver programs.
12. Feinberg, L.F., and Pillisuk, T. (1999). *Survey of fifteen states' caregiver support programs. Final report*. San Francisco, CA: Family Caregiver Alliance.
13. The vast majority of people with developmental disabilities of all ages live with their families. Yet as recently as 1998 only about one-third of all HCBS waiver participants with developmental disabilities lived with their families and an even smaller proportion (about 15 percent) lived in a home of their own. Within this overall average, however, there are large differences among states. In Arizona, for example, fully two-thirds of all beneficiaries with developmental disabilities who receive home and community services via the Arizona Long Term Care System live with their families.
14. Among individuals with developmental disabilities who live with their families, about 25 percent live with parents who themselves are older than 60.
15. Smith, G. (1999). *Closing the gap: Addressing the needs of people with developmental disabilities waiting for supports*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.
16. Smith, G. (1999). "Serving and waiting: An update" in *A supplement to closing the gap: Addressing the needs of people with developmental disabilities waiting for supports*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.
17. This type of HCBS waiver program is sometimes dubbed a middle-range program, because it fills the gap between limited state-funded family support programs and HCBS waiver programs intended mainly to buy specialized group-home and similar residential services.
18. HCFA was closely involved in reviewing the Illinois waiver program, since it replaced the program HCFA had cited in 1998-99 as being out of compliance.

Annotated Bibliography

Office of the Assistant Secretary for Planning and Evaluation and Administration on Aging (1998). *Informal caregiving: Compassion in action*. Washington, DC: Department of Health and Human Services. (31 pages)

A basic statistical chartbook with information and statistics on informal caregiving in the United States. *To obtain a free copy of this report, write to the Office of*

Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or via e-mail at DALTCP2@osaspe.dhhs.gov.

Arnos, P.S., Levine, C., and Memmott, M.M. (March/April 1999). The economic value of informal caregiving. *Health Affairs* 18 (2): 182-8. (7 pages)

Using large national data sets, this study explores the current market value of the care provided by unpaid family members and friends to adults with disabilities and chronic illnesses. Specific estimates for five states are also presented.

The National Alliance for Caregiving (NAC) and The American Association of Retired Persons (AARP) (1997). *Family caregiving in the U.S.: Findings from a national survey*. Washington, DC: Authors. (40 pages)

This report describes the various impacts of family caregiving in today's society, documenting the experiences and attitudes of persons who provide care to older Americans. The study is the first of its kind to address these issues systematically, using survey methodology, across four racial/ethnic groups within the United States: whites, blacks, Hispanics, and Asians.

To obtain a free copy of this document, write to AARP Fulfillment, 601 E Street, N.W., Washington, DC 20049. Be sure to include the stock number (D16474) and the title of the publication. Allow six to eight weeks for delivery.

LifePlans, Inc. (1999). *A descriptive analysis of patterns of informal and formal caregiving among privately insured and non-privately insured disabled elders living in the community*. Washington, DC: Department of Health and Human Services.

This report is based on a study of how long-term care insurance benefits are used, whether claimants feel they are getting good value for the premiums they pay, and whether patterns of formal (paid) and informal (unpaid) service use differ for long-term care insurance claimants compared to similarly disabled persons without long-term care policies. The report provides basic socio-demographic and service utilization profiles for both groups and discusses the implications of the study's findings for the service delivery system and for the design of private and public long-term care programs and policies. *To obtain a free copy of this report, write to the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or via e-mail at DALTCP2@osaspe.dhhs.gov.*

